BILLING Code: 4150-28P

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Request for Information on Guidance for the Specification of a Secure, Online Reporting System for

Streamlining Programmatic, Fiscal, and Other Data from DHHS-funded HIV Prevention, Treatment, and

Care Services Grantees

AGENCY: Department of Health and Human Services, Office of the Secretary, Office of the Assistant

Secretary for Health.

ACTION: Notice.

SUMMARY: The Department of Health and Human Services (DHHS) is seeking to identify interest and

obtain information relevant to the design, deployment, operations, maintenance, and future enhancement

of a centralized, secure, flexible data reporting system to streamline the collection, processing, and

sharing of programmatic, funding, and other data reported to DHHS Operating Divisions (OpDivs) by

grantees funded to provide HIV prevention, treatment, and care services.

DATES: To be assured consideration, comments must be received at one of the addresses provided

below, no later than 5 p.m. EST on [INERT DATE 15 DAYS FOLLOWING DATE OF

PUBLICATION IN THE FEDERAL REGISTER].

ADDRESSES: Electronic responses are strongly preferred and may be addressed to

[HIVOpenData@hhs.gov]. Written responses should be addressed to: U.S. Department of Health and

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Human Services, Room 443-H, 200 Independence Ave., SW, Washington, DC 20201. Attention: HIV Open Data Project.

FOR FURTHER INFORMATION CONTACT: Andrew D. Forsyth Ph.D. or Vera Yakovchenko, MPH, Office of HIV/AIDS and Infectious Disease Policy (OHAIDP), (202) 205-6606.

SUPPLEMENTAL INFORMATION:

In July 2010, the White House released the National HIV/AIDS Strategy (NHAS) for the United States that outlined four key goals: 1) reduce the number of people who become infected with HIV; 2) increase access to care and optimize health outcomes for people living with HIV; 3) reduce HIV-related health disparities; and 4) achieve a more coordinated national response to the HIV epidemic in the United States. Central to the latter goal were two related directives. The first was to develop improved mechanisms to monitor, evaluate, and report on progress toward achieving national goals. And the second was to simplify grant administration activities by standardizing data collection and reducing undue grantee reporting requirements for federal HIV programs.

In December 2009, the White House also released its Open Government Directive,² which seeks to improve access to government data in a manner that enhances transparency, fosters participation through the public's contribution of ideas and expertise to decision-making, and enhances collaboration through new partnerships within the federal government and between public and private institutions. Notwithstanding existing clearance requirements or legitimate reasons to protect information, the Directive highlighted the need for the following: 1) timely and accessible online publication of government information; 2) improved quality of government information; 3) creation of a culture of open government; and 4) establishment of a policy framework for Open Government. The release of the

¹ http://www.whitehouse.gov/administration/eop/onap/nhas

² http://www.whitehouse.gov/open/documents/open-government-directive

Directive was followed shortly thereafter by the DHHS Open Government Plan,³ which seeks to build upon the White House's emphasis on transparency, collaboration, and collaboration to ensure that the government works better for all Americans.

An important contribution of the DHHS Open Government Plan is its reference to new technological developments that make it possible to streamline the collection, sharing, and processing of programmatic and fiscal data in a manner that facilitates greater transparency, participation, and collaboration, even in such critical and sensitive areas as the DHHS investment in HIV prevention, treatment, and care services. At present, DHHS OpDivs that fund these services use a mixture of non-interoperable information processing systems to collect programmatic, fiscal, and other data from grantees. Moreover, these systems often utilize different indicators to monitor the progress of HIV/AIDS programs that vary in their specifications (e.g., numerators, denominators, time frames) and other key parameters. As a result, many required HIV/AIDS data elements are inconsistent, impede evaluation and monitoring of all relevant DHHS-funded services, and add undue burden to HIV services grantees charged with reporting obligations often from multiple DHHS OpDivs.

Under consideration at DHHS is the design, deployment, operations, maintenance, and future enhancement of a centralized, secure, flexible data reporting information system to compile programmatic, funding, and other data reported to DHHS OpDivs by grantees funded to provide HIV prevention, treatment, and care services. In effect, DHHS is exploring the possibility of establishing a single data reporting tool for funders, grantees, and sub-grantees that builds upon or shares many of the features of the Health Resources and Services Administration's (HRSA) Ryan White HIV/AIDS Services Report (RSR), which is a secure, online, data collection system for programmatic and fiscal data. Similarly, such a system might share features central to the National Institutes of Health's Electronic Research Administration (ERA), which offers a one-stop solution "to manage the receipt, processing,

³ http://www.hhs.gov/open/plan/opengovernmentplan/transparency/dashboard.html

review, award and monitoring of over \$30 billion in research and non-research grants" (see http://era.nih.gov). Moreover, such a system would offer a secure data solution that permits internal and external access to data, eliminates paper-based reporting, and streamlines the process of data collection and sharing in a manner that advances the DHHS Open Government Plan.

The HIV Open Data Project envisioned might offer several benefits, such as: 1) improve mechanisms to monitor, evaluate, and report on progress toward achieving NHAS goals; 2) ensure more coordinated program administration; 3) utilize a common protocol for establishing patient identifiers to protect confidentiality and de-identify client data; 4) reduce administrative and infrastructural costs associated with reporting to or maintaining independent data systems; 5) streamline and standardize data collection; 6) facilitate data sharing among federal and non-federal partners; 7) reduce bottlenecks and redundant data entry to different data systems; 8) integrate with electronic health record systems; 9) improve accountability and tracking of grantees with multiple funding streams; 10) facilitate data standardization and deployment of common core indicators that could form the basis of performance dashboards; 11) identify services gaps and unmet need; and 12) enhance transparency, participation, and collaboration around key public policy decisions relevant to the DHHS investment in HIV prevention, treatment, and care services.

Accordingly, this request for information seeks public comment on several key dimensions of such a project, including but not limited to the following:

1. In evaluating the feasibility of such a centralized data system, what specific steps would be critical to the design, deployment, operations, maintenance, and enhancement of such a system, particularly in light of addressing interoperability issues of existing data systems operated by DHHS OpDivs that support HIV prevention, treatment, or care services (e.g., Centers for Medicare and Medicaid Services, HRSA, Substance Abuse and Mental Health Services Administration, Indian Health Service, Centers for Disease Control and Prevention)?

2. What existing systems currently in use to monitor health grants offer the features desired and

what are the strengths and challenges of a) designing an entirely new online resource or b)

adopting an existing resource (e.g., HRSA's RSR or others)?

3. What are the greatest challenges encountered in reporting data (describe your reporting

obligations, if applicable) and what specific solutions have DHHS grantees implemented to

streamline divergent, non-interoperable reporting systems?

4. And what data would prove most useful for different stakeholders to receive from such a

centralized system?

5. What costs, benefits, and risks need to be given careful consideration in development of such a

resource? What are the estimated costs and return on investment of each component?

6. What technological resources and expertise would be needed to design, deploy, operate, maintain,

and enhance such a system and what extant models exist for achieving the goal of a secure

electronic resource capable of achieving the benefits noted above?

7. What system architecture do you recommend for the project, particularly considering the

government's desire to keep the project simple and streamlined (i.e. using as few different

software packages and tools as possible)? What architecture, expertise, and other components are

indispensible to the success of the design, deployment, operations, maintenance, and

enhancement of such a system?

8. What would a phased implementation plan consist of? If a modular or phased approach is

recommended, what is a realistic timeframe for the completion of the project?

9. What additional information not specifically addressed elsewhere in this RFI that would be

important for the government to bear in mind in developing such a system?

DATED: April 25, 2012

Ronald O. Valdiserri

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Deputy Assistant Secreta	y for Health	(Infectious D	Diseases)
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Office of HIV/AIDS and Infectious Disease Policy

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